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ABSTRACT

The booklet provides information on the early implementation of state protection and advocacy (P and A) systems as provided for and funded by Public Law 94-103 (Developmentally Disabled Assistance and Bill of Rights Act). The P and A implementing agencies are described in terms of the following characteristics: budget, staffing, use of resources, scope, visibility, amount of authority, and independence from service providers. Characteristics of a sample of nine states' (Florida, Idaho, Illinois, Louisiana, Maine, Minnesota, New Jersey, North Carolina, and Utah) implementation programs are included, as well as a chart with background data. Advocacy capability and initiatives (such as legal advocacy and legislative advocacy), the obstacles to implementation, as well as methods of assessing caseload and data collection are discussed. (PHR)

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STATEWIDE ADVOCACY SYSTEMS FOR THE DEVELOPMENTALLY DISABLED - PROFILES IN INNOVATION

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EXECUTIVE SUMMARY of Study Report
DHEW DEVELOPMENTAL DISABILITIES BUREAU
GRANT No. 54-p-71162/3

By

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American Bar Association
Washington, D.C.
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ABOUT THIS PUBLICATION

This is the second publication in the ABA Commission on the Mentally Disabled's study of the implementation process for federally-mandated systems of protection and advocacy for the developmentally disabled. It focusses on the actual start-up activities of nine differing state programs viewed during the first year of their existence. The protection and advocacy movement, triggered by federal legislation and fueled by special federal grant funds, is unprecedented in both its broad goals and its pace of implementation. Never before has such a massive and coordinated effort to ensure the availability of legal and nonlegal advocacy services to disabled citizens been undertaken. Given the critical and unique character of this effort, the Commission has been pleased to assist the Developmental Disabilities Bureau at the Department of Health, Education and Welfare in gathering as much data concerning the early stages of DD advocacy system implementation as possible. The full study report capsulized in this Executive Summary is in production and will be released in January, 1979 with special summaries of each of the nine states profiled and more than 40 data charts.

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This publication is part of a series that documents information on early implementation of state Protection and Advocacy systems. It was prepared and disseminated by the Developmental Disabilities Protection and Advocacy Review Project, a project of the ABA Commission on the Mentally Disabled. The project is funded in part by Grant #54-P-71162/3 from the U.S. Department of Health, Education and Welfare Bureau of Developmental Disabilities. The content herein does not necessarily represent the view of the Department of Health, Education, and Welfare nor may the content be construed to represent the view of the American Bar Association.

WASHINGTON, D.C.

DECEMBER, 1978

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PREFACE

In 1975, the federal government launched an extraordinary experiment in the stimulation and institutionalization of "client advocacy." Under the provisions and authority of the Developmentally Disabled Assistance and Bill of Rights Act of 1975 (Section 113, P.L. 94-103, 94th Congress), it provided funds to all 50 states to establish "Protection and Advocacy" systems for developmentally disabled citizens — defined at the time as children and adults afflicted with mental retardation, epilepsy, cerebral palsy, autism and certain learning disabilities (a potential national population, conservatively estimated, in excess of 5 million).

The P.L. 94-103 budget for the new P&A systems was a "shoestring" one (\$3 million nationally and \$20,000-\$40,000 for most states) and the technique for enticing state participation was bold and imaginative (making P&A a prerequisite for receipt of much larger state allotments for direct services and facilities for the developmentally disabled). Indeed, the Act was unique among federal grant-in-aid legislation in its requirement that states could not qualify for large formula grants in fiscal year 1978 and afterward unless they actually established an independent statewide system to pursue legal, administrative and other appropriate remedies for developmentally disabled persons receiving treatment and services in the state. The only precedent for such a comprehensive federal commitment to representation of disadvantaged groups was the much larger poverty law program administered by the Legal Services Corporation. This, however, was a direct federal program and could be distinguished from the pioneering locally-operated 50-state network contemplated by P.L. 94-103.

The federal "carrot" worked and, indeed, every state (and the District of Columbia and three territories) opted to develop a comprehensive advocacy plan, seek the modest federal grants available for implementation and launch their statewide P&A programs within striking distance of the statutory deadline of October 1, 1977. Now,

a year later, the program is in full swing, growing pains are of course evident, caseloads are hardly up to "critical mass," and statewide full-service coverage has been achieved in no state. Yet the wonder is that federally-supported, state-directed, professionally staffed, nationwide DD advocacy has become a reality in the space of two short years with an average annual federal investment of less than \$50,000 per state and an average staff of less than four full-time professionals per state. A critical factor for this "first-stage" success was, in many cases, the existing network of citizen volunteer and advocacy groups committed to the interests of each of the major DD categories and incorporated, at least in the state plans, as a major resource and partner to the necessarily small staff complements funded by the federal P&A grants. Another was a surprising infusion of additional resources and funds in these programs, even without hard and rigid federal matching requirements. Then, too, the DD world in each state, including the new P.L. 94-103 "State Planning Councils," had to see that these fledgling programs reached at least first base in order to share fully in the \$30 million in annual block grants authorized for direct services, care and facilities under P.L. 94-103.

Those of us concerned with client representation and advocacy in a number of arenas (poverty, mental illness, corrections, the aging) knew that this innovative program was something to be watched. Indeed, in early 1977, when the initial state P&A plans were being formulated, a delegation from the American Bar Association's Commission on the Mentally Disabled met with Assistant Secretary for Human Development Arabella Martinez and top officials of the DHEW Developmental Disabilities Bureau to emphasize the importance of the new Protection and Advocacy Program and to urge that DHEW take prompt action to track and lay the groundwork for evaluation of the new state systems, even before they became operational. The statutory mandate to the DHEW Secretary to develop a "comprehensive system of evaluation of services" provided under P.L. 94-103

(including the advocacy system grants) was stressed. We learned that these officials fully shared our concerns, and one direct product of the dialogue was the "pre-evaluation" study grant whose findings are reflected in this Executive Summary.

Specifically, the Developmental Disabilities Bureau, viewing the "rise" of the new P&A systems as a nationally significant research target, awarded a modest \$60,000 grant to the American Bar Association, working with the Council of State Governments as a major subcontractor, to examine the 50 state advocacy plans that had emerged and then to profile the "start-up" operations of a representative group of states during their first year of activity (or as much of it as could be encompassed within the grant's October 1977 through June 1978 research and field investigation program). That work has yielded two research reports, the second of which is summarized in this monograph, and constitutes the first attempt at evaluation of the state advocacy systems launched under P.L. 94-103.

The first report, issued in April of 1978 (**DD Protection and Advocacy: A Review of the State Plans**, 122 pp.) told us a great deal about the fifty state plans that had emerged from the first phase of the P&A program. These contemplated, for example, agencies that for the most part were under private auspices (typically non-profit corporations) or independent public commissions or councils, a wide variety of approaches to service delivery (direct and referral), utilization of existing advocacy and consumer groups to supplement small staff complements, heavy expectations for governmental and private funding to supplement P.L. 94-103 grants (dollars and in-kind) and a broad concept of the advocacy mission (legal representation, lay advocacy, systems and legislative reform, information and referral services, etc.). This inquiry confirmed what students of public administration know about comprehensive planning requirements in federal legislation — that paper plans are combinations of original grantee thinking, recitation of federal guideline requirements and concepts, and statements of intention that undoubtedly will undergo change (substantial and minor) in the crucible of "real world" im-

plementation. Nevertheless, the state plans served as an invaluable stimulus for "getting the act together" in the 50 states, working out timetables and organizational issues, and beginning to think about and address options of philosophy, approach and program that would inevitably be confronted in the implementation stages ahead.

This second and final report goes a step further. In it, Project Director Susan Weisberg traces the organizational history and emerging program experience of new P&A agencies in nine selected states — states which exhibit an illuminating range of diversity in size, location and P&A structure and evolution. The portrait is well developed and perceptively organized in this monograph and fully drawn in the complete study document soon to be released. What can readily be lost in the skilled and thorough report development, however, is the modest scale of the new agencies examined. Most are two- and three-professional offices serving the multifaceted and complex needs of large populations of handicapped citizens. Even the largest (Illinois with a record \$700,000 cash P&A Agency budget and three dozen professionals distributed among central office, legal, regional and residential posts) remains in the "modest agency" category by state government standards and even in comparison to smaller municipal operations. However, in the role of coordinators as well as service providers, one can see the potential and the emergence of vigorous, state-spanning advocacy programs — as yet, far more of a promise than a reality in every jurisdiction examined. And here lies the complexity of the evaluation, measurement and monitoring mission for the new P&A systems — how to examine the P&A agency as "nerve center" for a complex of advocacy activities in each state executed by organizationally connected and unconnected units (governmental and private) but without total examination of which it will be impossible to identify the true extent, impact and incidence of DD advocacy in any jurisdiction.

In this context, the nine state profiles featured in this report are both instructive and truly "profiles in innovation." While the field research schedule (completed in April) and the full research follow-up (completed in June) permitted close examina-

tion of no more than six months of actual operation in most cases, an attempt has been made to update budgets, staff complements and outcomes on key organizational and service initiatives to the end of the first federal fiscal year of P&A implementation (i.e., to October 1, 1978). This effort involved a chain of continued checking, rechecking and confirmation efforts, mostly by telephone, and the outcome offers, we believe, a quite current picture in the nine states studied to the start of the present fiscal year.

As a catalog of the usual and not-so-usual money, staff, political and program implementation issues confronting a new set of agencies working in the still young "client rights and advocacy" milieu (and being added as a dimension in so many social services areas), some of the profile findings are quite remarkable. It is clear for instance, that the P&A agencies (nationally and within the profile sample) spurred by the modest federal subsidy in P.L. 94-103, were able to find sufficient local interest and commitment to substantially augment their federal budgets, nearly doubling them on the average — a fact that augurs well for the federal leveraging goals of the P&A legislation. Moreover, feelings of independence, integrity and advocacy mission among the agencies seemed to fully comport with the "independence" objectives so solidly written into the legislation. On the other hand, it seemed equally clear in the sample that (i) a first year of activity was hardly adequate for any state to reach a full head of steam on service caseload and client accessibility (the caseload norm probably falling below the 50 percent level) or on full statewide coverage and availability, and (ii) no state had really been able to "take charge" or emerge as an effective coordinator of the full range of DD advocacy being advanced by public, private and volunteer groups within the state.

Perhaps equally significant, especially for evaluation and national accountability purposes, was the fact that emerging case reporting, data collection and program statistics formats (or lack of them) would, if permitted to continue, render impossible any meaningful (i) comparison of P&A programs and progress between states, (ii) aggregation of national statistics and descriptors on the

P&A systems and their output, or (iii) even meaningful analysis within states of the precise extent, character and total configuration of DD advocacy efforts.

These findings make a powerful brief for continued and more formal evaluation and monitoring undertakings with respect to the Section 113 DD Protection and Advocacy Systems. The ABA Commission is gratified that the Developmental Disabilities Bureau has already awarded evaluation contracts to carry forward this needed work* and believes that the focus on common baseline reporting and work measurement units, hopefully to be embraced by the state P&A programs, is a step of first priority and urgency.

The Association wishes to express appreciation to the Council of State Governments for its sub-contract assistance with the field research conducted in the profile states. While accepting full responsibility for this summary and all data and conclusions presented, the ABA Commission acknowledges the collaboration and assistance of Dr. William C. Main and attorney Clyde Simmons in the project's rather difficult field investigation mission, which produced valuable information, fostered a richness of insight, and made possible a geographic and institutional sample that went well beyond the initial grant project specifications (nine state profiles as against the six to eight states originally projected). Although primarily involved with other ABA responsibilities, invaluable assistance with the field interview effort was also rendered by Margaret A. Beer, Joseph F. Vargyas, and John C. Lamb of the Commission staff, each of whom visited at least two profile states. Ms. Beer, indeed, served ably for a substantial portion of this period as de facto "assistant project director" despite her student intern leave status from studies at Smith College.

Much is owed also to the project's funding and program oversight officials within the Devel-

* See DD Bureau Contract No. HEW-105-78-5002 with Harold Russell Associates, Inc. of Waltham, Massachusetts, authorizing an 18-month study commencing October 1, 1978 to, among other things, evaluate P&A implementation, establish tested performance standards, and suggest operational improvement measures.

opmental Disabilities Bureau — Ms. Doris Haar and Mr. Alfred Rose. Their splendid cooperation, their recognition of the importance of preserving relevant data about the initial implementation of protection and advocacy programs, and their patience in permitting some postponement of report submission to adjust for the slow pace of start-up in many agencies examined was essential to the productivity of this effort.

Finally, the extraordinary assistance of a host of busy P&A directors and state officials who provided the primary data source for this study merits heavy applause. This investigation, by its nature required repeated and intensive contact with many individuals who had precious little time to get on with day-to-day responsibilities no less respond to distant researchers. Without their cooperation, grace and understanding of the value of this kind of inquiry, the study effort could simply not have been completed. To Director Weisberg and her staff and Council of State Governments colleagues, their help was beyond the call of duty and in the best traditions of administrator/researcher collaboration. While a complete list is not possible, special recognition is owed to: Jon Rossman of Florida, Shirley Fritchhoff and Elizabeth Slusarz of Idaho, Stephen Schnorf of Illinois, Lois Simpson of Louisiana, Dean Crocker of Maine, Roger Strand of Minnesota, Herb Hinkle and Ethan Ellis of New Jersey, Al Singer and Elaine Robinson

of North Carolina, and Steve Swindle, Gordon Esplin, and Ineda Roe of Utah. These fine professionals not only gave liberally of their time in extended interview probes but served as our access points and schedulers for a host of other state official and interested party contacts.

Plutarch reported in the 1st century A.D. that

"The good have no need of an advocate" (Apothegms, Phocion)

Today, in 20th century urban America, our experience tells us that exactly the opposite may be true for many "good" men and women as they confront government and society and seek to fashion productive lives with integrity and enjoyment of the full rights and entitlements of American citizens. As we proceed with organized advocacy systems for developmentally disabled persons, it is essential that this proposition and a host of related issues (methods, financing, service mix, etc.) receive the closest scrutiny. The commitment to the value of such advocacy is clear; the test now is one of form, mix, effectiveness and "delivery of the goods" — a mission that requires both commitment and the best contributions of evaluative art and technology.

Daniel L. Skoler, Director
Public Service Activities
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EXECUTIVE SUMMARY

Introduction

Fiscal year 1978 marked the official start-up of Protection and Advocacy (P&A) systems for the developmentally disabled in most states. The states were complying with the mandates of the Developmentally Disabled Assistance and Bill of Rights Act, P.L. 94-103, which was passed by Congress in 1975 and contained two critical provisions. Section 111 of the Act set forth rights of the developmentally disabled, including rights to treatment, services and habilitation that would maximize an individual's potential and would be provided in a setting least restrictive of individual liberty and, where necessary, to residential services that comported with minimum standards for humane care. Section 113 of the law directed each state to establish a comprehensive system to protect and advocate for these and other rights of developmentally disabled individuals.

Each state "system" or network of advocates and advocacy services, was to have the authority and capability to pursue legal, administrative and "other appropriate remedies" on behalf of the target group. The governor of each state was to designate an agency responsible for implementing the new system and, to prevent conflicts of interest, the law required implementing agencies to be independent (i.e. free of the authority or influence) of state agencies providing "treatment, services or habilitation" to developmentally disabled people. Section 113 also made eligibility for receipt of federal DD service grants contingent upon state implementation of the P&A systems, which were to be in place by October of 1977. Three million dollars was authorized nationally for establishment of the systems in fiscal year (FY) 1978 (and for each of the two years in which P&A planning took place). This money was allotted to states according to the formula used for allocation of federal DD service monies under the Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517), which had been amended by P.L. 94-103.

At the federal level, oversight for P&A implementation was the responsibility of the Developmental Disabilities Office (DDO, now the Bureau of Developmental Disabilities) within the Department of Health, Education and Welfare (DHEW). All states and territories submitted plans for P&A implementation to DDO prior to start-up activities in early fiscal 1978. An analysis of the state Protection and Advocacy Plans for all jurisdictions is contained in a previous report of this project.*

Toward the end of the P&A planning phase, DDO recognized that program oversight as well as later program evaluation efforts would benefit from the collection of data on early P&A implementation. The American Bar Association's Commission on the Mentally Disabled, in conjunction with the Council of State Governments, was commissioned to document such data for a sample of nine jurisdictions. The states selected for this implementation review represent differences that could, it was hypothesized, influence ultimate program effectiveness. For example, there is a geographic distribution among the states and some are primarily urban, some rural. In addition, there is a distribution of public (state government) and private (non-profit) implementing agencies. Further, states receiving the minimum (\$20,000) federal P&A allotment and those receiving among the highest shares (greater than \$200,000) are represented in the sample. Included are the following states:

Florida	Minnesota
Idaho	New Jersey
Illinois	North Carolina
Louisiana	Utah
Maine	

* American Bar Association Commission on the Mentally Disabled, *Developmental Disabilities Protection and Advocacy: A Review of the State Plans* (Washington, D.C.: 1978).

Each of these states was visited twice during the first year of P&A implementation — once at the outset, and once at the midpoint of FY 1978. While the preponderance of data for the study reflect what had occurred by midyear, all states were consulted prior to publication of the final report so that major changes occurring before the end of the fiscal year (i.e. up to October, 1978) could be documented also. Indeed, staff and budget data have been updated to document a full year of operation and, as will be noted, the analysis reflects full year experience and progress in several other respects.

The full report contains a case study on each of the nine states. Each case study includes:

- Background information on the P&A implementing agency and its organizational environment
- Unique features of the state system and factors that seemed to enhance or impede its implementation
- Policy issues that emerged during the start-up phase
- Detailed data on P&A implementation:
1) implementing agency characteristics,
2) early caseload, 3) P&A resources, including facilities, personnel and revenues, 4) procedures for outreach, intake, referral/follow-up, data collection and system monitoring, and 5) the P&A "program" including types of advocacy services provided, specific types of intervention used, and training and technical assistance activities.

In its entirety, the report demonstrates the diversity of possible approaches to P&A system development. It is designed for users within the P&A systems who have a need for detailed information on program operations as well as for public administrators, legislators, researchers and others with interests in policy, program development and evaluation.* Since it describes what states have been and can be doing, the report should prove a useful tool for consumers and consumer representatives in assuring effective advocacy initiatives in both sample and non-sample states.

The following text offers summary information from the review of P&A implementation in the nine states.

Implementing Agency Characteristics

The review of implementation has been conducted from the perspective of the P&A implementing agency. Thus, it is important first to provide background information on these agencies in the nine states — who they are, what resources they have at their disposal, the variations among them in resource use, their ability to be visible and to provide services statewide, the authority by which they were established, and their independence of service providers as mandated by the law.

The chart following this page presents a series of background data for the sample states.

The Implementors

Among the nine states there are four public and five private P&A implementing agencies.

The public implementors include: a Governor's Commission (Florida) and a Governor's Council (North Carolina) — each attached to a state Department of Administration; and two executive agencies — the Minnesota State Planning Agency and the New Jersey Department of the Public Advocate. Both of the latter states had established advocacy programs prior to passage of P.L. 94-103, thus many typical start-up activities did not occur during the 1978 fiscal year for these jurisdictions.

* For those interested in P&A monitoring and evaluation, the full report contains an Appendix listing data sought for the study.

DD PROTECTION AND ADVOCACY IMPLEMENTING AGENCIES AND THEIR FY 1978 RESOURCES

STATE	IMPLEMENTOR * = Public agency; others are private	BUDGET			PERSONNEL			FACILITIES S = Single site M = Multiple sites
		Cash Revenues Available	% P&A ^a	Other Sources ^b	Professionals/ Paraprofessionals Under Agency Administration/ Supervision ^c	Other	Total	
Florida	*Governor's Commission; Established by executive order	\$115,299	100	In-kind (state)	2*	1 Support	3*	S
Idaho	Open membership corporation	172,087	12	CETA DD Council In-kind (VISTA, private)	19	1 Support (15 Volunteers)	20	M
Illinois	Established by executive order; has contracted project operations	692,867	26	CETA; HEW/DDO; DD Council; State; In-kind (state, private)	12 In agency* 24 On projects	8 Support*	44*	M
Louisiana	Official implementor is legal assistance corporation	132,139	75	CETA DD Council Private In-kind (private)	6*	3 Support*	9*	S
Maine	Open membership corporation; established by exec. order	44,584	45	CETA; DD Council State Membership Dues In-kind (state)	4	1 Support (75 Volunteers)	5	S
Minnesota	*State Planning Agency; has contracted project operations	213,168	23	CETA; HEW/DDO; DD Council In-kind (state, private)	3 In agency* 16 On projects*	3 Support* (200 Lay Advocates)	22*	M
New Jersey	*Agency is under state Dept. of the Public Advocate, which has grants for project operations	299,500	27	HEW/Region II HEW/RSA DD Council In-Kind (state)	9	3 Support	12	M
North Carolina	*Governor's Council; estab- lished by statute to serve developmentally disabled and mentally ill	129,662	63	DD Council In-kind (state)	7	1 Support	8	M
Utah	Legal services agency; state supreme court order autho- rizes provision and publicity about legal services	56,821	72	Title XX DD Council Private Fee for services	3*	1 Support	4	S
AVERAGE	—	\$206,236	49	—	12*	2	14*	—

^a Includes the FY 1978 P&A allotment (a total of \$549,528 for the nine states) plus any P&A monies encumbered in and carried over from FY 1977 (totaling \$136,051 for the nine states)

^b Additional sources were considered or were sought by the agencies in FY 1978, but were not secured. These included: the federal Bureau of Education for the Handicapped, the Mott Foundation, the ABA Bar Funding Program, and a state Humanities and Public Policy Council.

^c Includes agency directors

* Includes some part-time personnel

Though they all have public agencies, the four states have selected quite different organization models for P&A implementation: New Jersey's is a line agency with direct authority over various advocacy programs including the project office responsible for DD advocacy; Minnesota's implementor is a staff (or administrative support) agency that plans and coordinates direct service delivery by private organizations under P&A supervision, and also coordinates activities with state government advocacy units; in North Carolina, a staff agency is responsible for policy and program coordination for a variety of advocacy programs, including that of the DD Advocacy Council; Florida's Commission is not part of a multi-program advocacy network and its attachment to a state government department is exclusively for administrative purposes.

Among the five private implementing agencies, two are legal services programs: the Louisiana organization established a component unit for DD advocacy; the Utah organization was expressly created for legal services to the developmentally disabled. The remainder of the private agencies (in Idaho, Illinois, and Maine) are non-profit corporations established specifically to implement P.L. 94-103.

Budget, Staffing and Resource Use

The average FY '78 budget for the nine agencies is approximately \$206,000, 58 per cent higher than the \$130,000 national average projected initially from P&A Plans.* The most typical budget range for all jurisdictions, according to the Plans, was from \$25,000 to \$50,000 and one sample state, Maine, falls within that range. Included in the sample are three states that received the minimum federal P&A allotment of \$20,000 for FY '78 and the single best-endowed P&A agency, that in Illinois, with total cash revenues from all sources of nearly \$700,000.

On the average, P&A allotments accounted for 49 per cent of the financial resources for sample states in FY 1978, somewhat less than the 52 per cent national average calculated from state Plan information. These figures, further, do not include

in-kind resources that also were made available to the agencies, supplementing dollar revenues in some cases by over 30 per cent.

Among the sample states, three had only P&A monies to work with during the first half of the year, but only Florida relied solely on its P&A allotment for the full year. Remaining states had tapped from one to four sources of money in addition to P&A funds. These sources included: CETA, special grants from DDO and from the Rehabilitation Services Administration of DHEW, State DD Planning Councils, state governments and private sources. Aside from resources initially available to them in FY '78, most agencies were actively seeking additional money and/or staff at midyear. Others, such as Florida or Illinois, which did not require added money, were contemplating sources that might be used in FY '79. Among new sources pending or contemplated at midyear were: Title XX of the Social Security Act, VISTA, the Federal Bureau of Education for the Handicapped, the Legal Services Corporation, the ABA Bar Funding Program, the Mott Foundation, Community Trust/United Way, and a state Humanities and Public Policy Council. In addition, three agencies were considering a fee for legal services (Illinois, Maine and Utah) and one (Maine) was considering corporation membership dues.

The variety in P&A program models becomes evident as resources (budget and personnel) and their use are considered together in an overview of: 1) states with minimum P&A allotments, 2) other states falling within a "medium" budget range for the sample, and 3) the sample states in the "high" budget range (greater than \$200,000 for the year):

The minimum allotment states have \$20,000 each in FY '78 P&A monies and have done the following:

- Idaho increased its budget to over \$100,000. It supplemented P&A resources with CETA and VISTA staff, bringing a February total of 11, and later 19, professionals or paraprofessionals under its direct administration and launching an effort to

* Review of the State Plans, *supra*.

recruit nearly 60 volunteers. The agency has a statewide outreach capability and focuses on non-legal case advocacy.

- Maine remains in the low budget range for the sample (under \$50,000). It began with a professional P&A director and one support staff person who, unlike support staff in many agencies, also handled programmatic responsibilities. CETA money was used for hiring two additional staff during the second half of the year, and an attorney was hired under contract toward year end. Activities during the start-up phase were aimed at recruiting a goal of 90 volunteers to handle non-legal case advocacy with emphasis on crisis intervention and protective services.

- Utah also remains in the low budget range and began with a staff of two lawyers, later aided by a student law clerk and a secretary. Early efforts included preparation of a legal rights manual and provision of legal services to individuals, while other types of advocacy remained the province of existing organizations and agencies. By year end, the Utah agency had filed four lawsuits, one of them a class action.

In the medium budget range, Florida and Louisiana have nearly identical total funds; however:

- In Florida, as noted, P&A money is the only source of funds. There is one full-time professional staff person, a lawyer-director, who serves the advocacy commission. The P&A focus is on building a statewide legal advocacy capability during the first implementation year and a substantial portion of the budget is thus devoted to 1) contracts for training and preparation of legal rights training materials, and 2) a litigation fund that by the end of the year was being used for three lawsuits.

- In Louisiana, P&A money represents 84 per cent of total funds. Personnel expenditures at midyear supported five full-time professionals, including two lawyers. While there is a P&A priority for direct service in individual cases, one of the agency's main contributions has been as a facilitator for local systems advocacy efforts. By the end of the

year, this agency was preparing a lawsuit against New Orleans officials for the city's purchase of buses inaccessible to the handicapped.

- North Carolina represents the middle ground of the medium range. Its resources are divided between 1) personnel expenditures that make possible direct services (non-legal, legal, and systems advocacy) by a medium-sized staff including the lawyer-director, and 2) expenditures for training and legal services through contracts with outside groups (which initiated two lawsuits by year end). During the year, the agency increased its staff and began providing services on a regional basis.

A common feature among agencies in the high budget range is that all have grant or contract operations for direct advocacy service delivery. However, the nature of these operations as well as that of the core P&A component differs among three states:

- In Minnesota, core staff are principally planners, administrators and program monitors. Contract operations include legal service delivery and citizen advocacy, some of it focused on persons in contact with the criminal justice system. Experimental models for both types of advocacy have been implemented in a rural area of the state. The state's long-active legal advocacy component initiated legal action in several cases during FY '78.

- In Illinois, there is a greater differentiation of core staff, with some exercising supervisory responsibility for P&A contract operations, some performing other specialized staff functions (e.g. parent training, information services) and some engaged in direct delivery (field advocates). Contract operations provide legal services, non-legal case advocacy, and in-house advocacy for residents of state facilities. At least 10 P&A cases in this state had required court action by year end.

- In New Jersey, core staff includes lawyers and other professionals who provide direct advocacy services. Grant operations include monitoring of the deinstitutionalization process at a state facility, with facility-based assistance to individuals in transition to the community, and legal and non-legal advocacy for clients of an urban county vocational rehabilitation system.

Each Protection and Advocacy system is to be statewide in impact and is to be known to those who can benefit from its services. These objectives are discussed below.

Statewide Scope and Visibility

All P&A agencies in the high budget range and two of those in the medium range operate from multiple sites. (According to P&A Plans, eleven states across the country will have multi-site operations.) However, due to the nature of some regional operations (e.g. those that are experimental or located in one facility only, etc.), this does not mean that a given type of advocacy service will be equally available to all state residents who may need it. This may be characteristic of the start-up phase for many new programs and particularly those with as small a federal investment as had been made in protection and advocacy. Several P&A models do or will ultimately assure uniformity of service throughout the state. Jurisdictions with this type of regional model include: Idaho (with an office in each of the state's Health and Welfare regions), Illinois (with a series of local offices for each type of project operation — legal offices throughout the state, residential advocates in each facility with population of a given size, and area-wide non-legal advocacy projects in each of the state's regions as well as subregions of Chicago, these to be phased-in over a five year period) and North Carolina (with four planned regional offices).

In other states such as Florida, Louisiana and Minnesota (prior to implementation of its rural demonstration projects), relatively high travel expenditures were required to assure contact with consumers and advocates distant from the central P&A office. In Utah, which has only a single site, reservations were expressed about the ability to reach a dispersed disabled population in rural areas that comprise the bulk of the state.

Attempts at outreach to special populations had been made in several states (e.g. there was an advocate serving Appalachian counties of North Carolina, which have relatively high MR populations, and Minnesota had made some attempt to reach reservation-based Native Americans.) Only

in Idaho however, was a full-scale effort initiated, in this case using seven VISTA community organizers to reach the rural disabled.

"Public awareness" campaigns were also a common feature of early implementation in some states. Such campaigns might include statewide publicity of various sorts on legal rights and on services available through the P&A system. In most cases these efforts have been planned and/or carried out by the P&A agency in conjunction with a state DD Council.

However, P&A representatives in at least five states expressed concern about the impact of publicity on the demand for advocacy services. Nearly all stated this in the same way: that they did not want to create expectations that could not be fulfilled. Doing so, they felt, would severely jeopardize the chance for P&A effectiveness. Florida had thus postponed any large-scale public awareness efforts until the second year of operations. New Jersey staff reported that demand already exceeded staff capacity to respond and, by the end of the year, the agency had virtually halted intake of some types of cases. This was said to be a difficult bind where other resources (e.g. citizen or lay advocacy networks) were insufficient to handle any excess demand. Several agencies noted that such resources were not organized in some or all parts of the state, or were weak or nonexistent (e.g. where there were no organized consumer groups for certain of the developmental disabilities). Such problems were mentioned in Illinois, Maine, and North Carolina as well as in New Jersey.

Still, information about rights and P&A services was distributed to the general public and to other advocates through various means. The agencies uniformly distributed brochures to interested parties, usually beginning with service providers who could make referrals to the P&A system. In most states, clients had access to the P&A agency through a toll-free phone number or "hot line." In addition, several states had clearing house operations for the exchange of information, several prepared newsletters, and others had developed or were developing pamphlets, training materials or similar documents that could be used in orienting groups to legal rights and in supporting the advo-

cacy efforts of organizations and individuals outside the P&A agency. The table below shows which of these "information services" was available in each of the states at midyear.*

Agency Authority and Independence

All advocacy agencies, whether public or private, have been designated official P&A implementors by their respective state governors. All governors were required to assure DHEW that the agencies would have sufficient authority to carry out the remedies mandated by P.L. 94-103 and that they would be independent of service providers.

Apart from governors' statements to DHEW, P&A authority is legitimized in three main ways: 1) by a governor's executive order giving the agency official state recognition, 2) by state statute vesting

the agency with specific powers and duties and/or 3) through corporate charter, again providing official state sanction to the P&A mission described in private agency by-laws.

The five private agencies in the sample are chartered non-profit corporations and two of these (Illinois and Maine) were designated by executive order to be official state P&A implementors. Among the public agencies, one was established by executive order (Florida) and two were statutorily-created (New Jersey and North Carolina, the latter authorized to serve both the developmentally disabled and the mentally ill). The Utah agency gained some additional legitimacy through a state supreme court order authorizing delivery and publicity about legal services to the developmentally disabled.

P&A "INFORMATION" SERVICES AT MIDYEAR

* = In progress
** = Planned

STATE	"Hot-Line"	Clearinghouse Services	Newsletter	Other Documents
Florida		•		Transmittals on specific issues Directory of Advocacy Resources* Legal Rights Information Booklet (non-technical)* Continuing Legal Education Manual (technical)
Idaho	•		•	
Illinois	•	•		Procedures manual Advocacy manual** Parent training curriculum materials
Louisiana	•**			Regional resource directories*
Maine	•	•		Advocacy training materials**
Minnesota	•	•		Advocacy manual Legal rights brochures Directory of statewide advocacy services**
New Jersey	•			Legal rights training manual*
North Carolina	•		•	Rights of the handicapped (handbook)*
Utah			•**	Legal rights training manual* Directory of advocacy services**

* After the middle of the year, federal funds were made available to finance "hot lines" for agencies with a need for such service.

By the middle of fiscal 1978, there were five states nationally that had enacted DD advocacy statutes in response to P.L. 94-103.* Among the nine-state study sample however, no state succeeded in securing new legislative authority during the first year. However, lawmaker support had been or was being sought in some of the states, and in some, measures related to DD advocacy were being considered. Supporting the P&A concept for example, the Illinois legislature passed a bill for a mental health advocacy system (which would include legal and public guardianship services, as well as a series of human rights authorities). New Jersey staff were assessing support for a move to amend their state's law such that it would officially recognize the DD advocacy unit and clarify that unit's authority. Only in Florida was a DD advocacy bill actually introduced during the year. Though several influential legislators in Florida are DD supporters, a bill to expand powers of the P&A Commission was defeated. Thus, for the sample states at least, P&A authority remained as it was initially.

The issue of P&A independence was raised in several states and in various ways. Advocacy representatives were concerned not only about actual freedom from state or service provider influence but also about the image of P&A independence held by consumers and the public at large. Actions during the P&A planning stage had been seen by some as potential threats to independence (e.g. gubernatorial moves in both Florida and North Carolina to establish public agencies rather than the private non-profit implementors favored by planners or other interested parties). Minnesota's proposed organization had been challenged by DHEW on the grounds that the P&A director was shown as reporting to a "service provider" group, the state DD Council.

In the early implementation stage, concern persisted about gubernatorial response to P&A activism. In Florida, uncertainty was allayed when the Executive Office approved P&A contracts for actual litigation to be handled by independent legal services programs. In North Carolina, P&A concern was somewhat counter-balanced by expressions of strong support from several Executive Office officials, and by their backing for a P&A move that might have proven controversial for the

governor. In Illinois, where the P&A implementor is a private agency, there was similar concern. In that state, at least one member of the governor's staff has urged that the governor be allowed to intervene as a last step before any litigation against a state department. Also in Illinois, there was a perceived threat to the independence of P&A institutional advocates due to the nature of agreements between the P&A agency and residential facilities operated by the state's Department of Mental Health and Developmental Disabilities. In Minnesota, a fairly recent government study proposed placing all public advocacy functions under a human resources agency, an action that would clearly violate P&A independence. On the Idaho P&A board, questions were raised about a possible over-representation of private service providers and one member agency withdrew for the stated reason of promoting a better balance.

In at least three states, there was a concern about actual compromise or the appearance of compromise that might result from acceptance of certain funds, including those from DD Councils. Given the limited federal investment in P&A and the inability of most systems to benefit from state general revenues or to always compete successfully for other federal (e.g. Title XX) or private (e.g. foundation grant) resources, the agencies foresaw an effectively limited number of "neutral" money sources. For example, Maine planners, who were vocal about P&A independence from all government influence, also found it necessary to request a first year state contribution to help while the goal of financial independence was being pursued. In New Jersey, P&A representatives wondered whether sustenance or expansion of advocacy systems would be possible without reliance at some point on provider money.

Concern about the image of independence was revealed in yet other ways. The North Carolina "hot line" service for example, was operated by a

* These included: Connecticut, Indiana, Kentucky, North Carolina and Michigan. The New Jersey statute referenced above predated passage of P.L. 94-103. A review of DD advocacy legislation is contained in the third report of this series. In addition, a model state advocacy statute has been published by the ABA's Commission on the Mentally Disabled as part of a series of model statutes advancing the rights of the developmentally disabled. See DD State Legislative Project, *Advocacy for Developmentally Disabled Persons*, 39 pp. (Jan. 1979).

government provider agency. It was mentioned that consumers might think the Advocacy Council too, were linked to the provider. In Idaho, the P&A central office was located apart from government buildings to preserve the image of independence.

Advocacy Capability and Initiatives

According to P.L. 94-103, P&A systems must have the capacity to pursue "legal, administrative and other appropriate remedies" on behalf of the developmentally disabled. Since the P&A agency is the one held accountable for implementation, it is important to look first at the role of that agency in the system and its own capability for conducting advocacy of various types. Beyond that, the most significant questions for a review of implementation are: 1) what specific initiatives were undertaken by the agency, alone or in conjunction with others, during the start-up phase, and 2) what obstacles, if any, impeded the implementation effort.

P&A Capability

Advocacy classifications and definitions normally tend to be somewhat arbitrary and to overlap. For example, any type of representation on behalf of an individual may be thought of as "case" advocacy. However, when such representation is undertaken by a lawyer in a judicial proceeding, it would be termed "legal" advocacy, and when by a volunteer assisting someone to secure services it might be a type of "citizen" advocacy. Several broad classifications have been selected here in order to provide a general look at what P&A agencies can and have chosen to do; the categories are:

- **Systems advocacy**, including efforts to influence or change policy or practice

of government or private organizations as it affects groups of developmentally disabled people

- **Legal advocacy**, narrowly defined as a capacity to pursue judicial remedies due to the presence of lawyers on the P&A staff or as part of grant or contract operations

- **Other individual advocacy**, including administrative and other non-judicial remedies pursued primarily by professionals, paraprofessionals or volunteers who are not lawyers

- **Legislative advocacy**, encompassing specific efforts to monitor, draft, testify on, or otherwise influence legislation that affects the developmentally disabled

- **Other specialized advocacy**, including special initiatives designed to benefit subsets of the developmentally disabled population

Though no agency had a specialized program component or project to undertake systems advocacy, nearly all placed some priority on this activity. Exceptions included Idaho and Utah. In Idaho, staff had engaged in health planning efforts, but the main responsibility for systems advocacy was seen to rest with the state DD Council. In Utah, existing organizations were said to be doing an adequate job and systems initiatives were not made a priority of the implementing agency.

Legal advocacy capability, through staff or grant/contract operations, existed in all states but Idaho and Maine. In neither of these states did formal arrangements exist for the provision of legal services, though legal advice could be obtained and referrals made on an informal basis. Plans for the P&A systems in both states called for services of a full-time attorney but in Idaho the plan had been implemented by the end of the first year, and in Maine it was implemented only as the year drew to a close.* Legal services are provided

* At the end of the fiscal year (mid-September, 1978, with money from its state vocational rehabilitation department, Maine contracted with an attorney who would serve the department's clients and others who might need VR services.

by contract or grant in Illinois, Minnesota, North Carolina, New Jersey and Florida. Attorneys are on staff in the latter three states and in Louisiana and Utah.

Individual advocacy of an administrative or non-legal nature is conducted in nearly all states: by professional or paraprofessional staff as in North Carolina, through special projects as exist in Minnesota and Illinois, and/or through auxiliary volunteer networks as were being developed in Idaho and Maine. Because adequate non-legal advocacy resources exist outside the P&A agencies in Florida and Utah, both rely on ancillary agencies for this service and concentrate their own efforts on legal or legislative activities.

Legislative advocacy was considered a role of the P&A agency in six of the states. In the others, no legislative initiatives had begun or were contemplated for the first year.

Examples of other specialized advocacy efforts include project operations in the large states (e.g. residential advocacy in Illinois and New Jersey), community organization among and services to the rural disabled in Idaho and Minnesota respectively, and work toward community placement of retarded offenders in Maine.

P&A Initiatives

While "capacity" refers to the ability to take action because sufficient resources are in place, more significant is what specific intervention has occurred. The chart on the following page depicts P&A system initiatives in the nine states during the first half-year of operation. Information is presented in terms of:

- Type of action taken, whether individual advocacy of a legal or non-legal nature, legislative advocacy, or systems effort such as participation in planning or rule-making, issuance of policy statements, etc.
- Substantive areas addressed, such as zoning, guardianship, admission or access to services or entitlements, etc.

The chart then takes into account the variety of substantive issues addressed by the agencies and it gives some notion about the variety of means employed to address them. It does not account however, for the volume of cases or activity in each category. Case volume is treated in a separate section of this summary and more detail on specific P&A intervention is found in the full report.

The half-year start-up record of specific intervention activity within the nine-state sample indicates that:

- Education was the only substantive area in which all states had intervened and nearly all had done so through individual cases only. Actions against discriminatory practices and in favor of admission to services were the next most common areas for individual advocacy.

- Legislative efforts had occurred in all but three substantive areas (personal rights, admission to services and criminal justice). Action on zoning had taken place or was being planned in three states, as was action on guardianship. Environmental barriers had been addressed in two states, and in each other substantive area receiving attention, action had been taken in one jurisdiction.

- In some substantive areas, systems efforts had been conducted by nearly as many states as had been involved in individual cases. This was true of action on discrimination, admission to services and rights in residential facilities.

- According to the available data, the state with the longest history of advocacy experience, Minnesota, was the only one to have intervened in all substantive areas; New Jersey, the state with the second longest history, had intervened in eight out of nine areas; and Florida had taken initiative in seven. Interestingly, the P&A implementors in all three of these states are public agencies. Other states had experience at midyear in the following numbers of substantive issues: Louisiana and Maine (6), North Carolina (5), Idaho (4), Illinois and Utah (3).

TYPES OF P&A INTERVENTION AS OF MID-FY '78 BY SUBSTANTIVE ISSUE

(● = Individual Advocacy ★ = Legislative Advocacy ■ = Systems Advocacy)

STATE ISSUE	FLORIDA	IDAHO	ILLINOIS	LOUISIANA	MAINE	MINNESOTA	NEW JERSEY	NORTH CAROLINA	UTAH
Education	●	●	●	●	● ■	● ★ ■	● ■	● ■	●
Zoning	★		●	★		★	■		
Guardianship	★		●			● ★	● ★	●	
Right to Services/Other Rights in Residential Facilities*	●				■	■	● ★ ■	●	
Discrimination: Employment Housing Other	■	● ●		● ■	● ■	●	● ■ ●	● ■	● ●
Environmental Barriers: Transportation Other		● ■		■	■	★	● ■ ● ■		●
Criminal Justice Issues	●			★ ■	● ■	●			
Personal/Civil Rights in the Community			●	★		● ■	●	●	
Admission to Services	●	● ■		■	● ■	● ■	● ■	●	

* includes the issue of deinstitutionalization

Chart Definitions and Legend

Examples of P&A intervention as recorded on the chart (by substantive area and type of advocacy) include the following [and where examples are fairly unique, this is noted]:

- Education
 - (I): representation at a hearing on implementation of an Individual Education Plan as called for under P.L. 94-142 (the Education for All Handicapped Children Act)
 - (S): efforts to assure implementation of a corresponding state statute
- Zoning
 - (L): work toward a state law governing placement of group homes in residential areas
- Guardianship
 - (I): a P&A representative acting as guardian ad litem for a disabled person or persons in a specific court proceeding
- Right to services and other rights in residential facilities
 - (I): establishing the right to judicial review of treatment (N.J.), challenging the cost of care (Fla.), following-up on cases referred to institution-based advocates (Maine)
 - (S): monitoring the deinstitutionalization process conducted by state agencies (N.J.), commenting on or drafting state rules on costs or reimbursement for long-term or intermediate care (Maine, Minn.)
- Discrimination
 - (I): assisting with individual claims of employment discrimination in violation of sections 503 and 504 of the Rehabilitation Act, challenging discrimination in housing or payment of federal benefits
 - (S): attempting to prevent construction of facilities segregating the retarded from other school children (N.C.)
- Environmental barriers
 - (I): assuring access to transportation for handicapped individuals
 - (S): supporting revised building code requirements (Idaho), challenging municipal purchase of buses inaccessible to the handicapped (La.)
- Criminal justice issues
 - (I): challenging parole revocation for a retarded offender (Fla.), providing advocacy services to victims, witnesses, accused and convicted disabled persons (Minn.)
 - (S): participating in a coalition of advocates for juvenile justice (La.)
- Personal/civil rights in the community
 - (I): handling cases of consent for surgery, protection against abuse, challenge to vehicle licensing and insurance requirements
 - (S): participating in a task force on sterilization (Minn.)
- Admission to services
 - (I): assistance with and challenges to admissions procedures for residential facilities and access to public and private entitlements (medical, financial, diagnostic, etc.)
 - (S): participation in health or other human services planning, monitoring state service delivery programs, commenting on state or federal regulations

In addition to the foregoing initiatives, a variety of training activities was underway by the middle of the year. Training was aimed at professionals, consumers and parents/guardians of consumers, citizens interested in advocacy, etc. Some activities were formal (e.g., a statewide conference in Florida), some informal (e.g., in many states, workshops and speeches by P & A staff to small groups). Topics of the training sessions included substantive legal rights as well as advocacy techniques. Specialized training materials had been or were being prepared in seven of the states and in three (Florida, Maine, and North Carolina), contractors were assisting with some or all parts of the P & A training program.

Factors influencing the recorded breadth of experience in some states include the following:

- delays in start-up activities
- other obstacles to system implementation
- extent and detail of caseload data and other documentation on P&A operations

These subjects are discussed in the following sections.

Obstacles to Implementation

By now, many people are familiar with the "systems" terminology first borrowed from the computer sciences field and since then applied to human service "systems". It will be useful in examining obstacles to P&A implementation. The approach uses four basic concepts to describe components of a system: 1) resource "inputs", 2) a "process" in which the inputs are used, and which produces 3) system "output", or results; and 4) a set of "external factors" which may impinge on the system and affect output.

In this case, "external factors" are those not subject to control by P&A decision-makers and include such things as: state political and economic conditions, geographic and population characteristics, federal and state policy, resource availability, and so forth.

"Inputs" include money, personnel, equipment and facilities. The "process" is implementation. it-

self: conducting advocacy efforts to protect rights of the developmentally disabled; the "output" will be an increase in rights exercised by developmentally disabled people. Questions of output belong in the realm of program evaluation, which is beyond the scope of this study; the advocacy process, in terms of actual activity, was discussed in the previous section. Examining impediments to that process requires looking at external factors and taking another look at resources within the P&A systems.

The most obvious external influences are the federal law that mandated states to do something and the very limited federal money that was made available to assist them in doing it. The monetary limit was not necessarily an obstacle in itself: it was not the intent of Congress to create new state bureaucracies but rather, to establish agencies that could draw together existing advocacy resources (organizations, agencies, individuals), increase their capability and fill gaps where necessary. But the second, and sometimes problematic, external factor is the availability of advocacy resources (and potential resources) within the state. Some of these problems have been highlighted (e.g. the lack of citizen advocacy programs in some states, or the lack of activist consumer organizations, sometimes in areas of a state with the greatest need). The Louisiana P&A agency found that the state's one group of citizen advocates needed more skill in providing practical assistance to individuals and in following through on specific cases. Until these skills were developed, P&A intervention was required, diverting resources from other tasks.*

The availability/capability of existing resources can present other types of problems. For example, in Florida it was noted that preparation of certain legal rights materials was made difficult because no lawyers within the state yet had enough practi-

* Another external factor was a series of federal grants awarded to organizations in each DHEW region to provide technical assistance to state P & A systems. These grants were not always considered effective by P & A staff, however (e.g., because required assistance, such as legal help, was not available through the grantee [Idaho]; because grantees were thought to request more information than they provided [Florida]; or because experience equal to or greater than that of the grantee organization was thought to exist in the P & A system [New Jersey]).

cal experience in DD law. In Idaho, action on public awareness and on systems advocacy was somewhat delayed because of initial P&A conflicts with the DD Council over the role to be played by each organization. In North Carolina, the DD Council was perceived as remote from P&A and coordination between the two groups was not extensive. Louisiana found existing "hot line" services inadequate for P&A purposes, and the implementing agency devoted effort to establishing such services of its own.

Even where advocacy organizations do exist in sufficient quantity or strength, there may be conflicts among them that pre-date establishment of an advocacy system and remain to influence its implementation. In a loose sense, these may be viewed as external political factors and they had a bearing in at least two states. Idaho's initial P&A board was a coalition of existing voluntary advocacy organizations. While they shared a common purpose, these organizations normally were competitors for funds and other resources, which hampered their ability to coalesce in support of yet another organization, the P&A agency. By midyear, the coalition had been dissolved in favor of a different board composition. In Utah, an influential senator heads an organization that has supported institutionalization. The senator initially opposed establishment of the P&A system and later vied for a seat on its board. Though he was not installed, a compromise was reached whereby another of the organization's representatives would serve.

Factors such as those mentioned produce an impact on P&A policy and therefore on the P&A "process". Other external factors are political in a stricter sense of the word, and also may be more significant for the affected states. For example, appointment of the North Carolina implementing body, an advocacy council, was severely delayed because the state's new governor was responsible for literally hundreds of appointments as well as other priorities of a new administration. This meant a postponement in some P&A priority-setting and delay in taking action that would require the political clout of an appointive council. At the other extreme, executive support accorded other agencies may be affected by this year's transition in governors.

State policy is another external influence on P&A systems, and particularly on the public implementors. The New Jersey agency's access to state money, for example, is officially limited by a five per cent ceiling on annual appropriations increases to a single department. Staff recruitment in North Carolina was significantly delayed by state civil service system policies and procedures.

Other external factors, noted earlier, included geography and dispersed populations in the rural states and in some others (e.g. Florida and Louisiana) with single-site operations.

Input problems normally involve lining up and keeping resources. Finding money was a concern in most states and was discussed earlier. Keeping money was somewhat of a concern in Illinois where board appointment was delayed by a month and where lengthy contract negotiations delayed implementation of (and therefore expenditures for) legal, citizen and residential advocacy components.

Personnel recruitment and turnover delayed or disrupted some operations. For example, volunteer recruitment in Idaho was delayed because of staff attention to individual cases, a VISTA attorney was assigned to the agency and reassigned elsewhere, and there was a turnover in directors at midyear. Some anticipated student help did not materialize in Louisiana causing postponement of a planned project. The Maine agency was seeking staff at midyear to undertake new tasks and to carry out some functions originally intended for the P&A board. The North Carolina agency could not recruit staff for the reason noted above, and Utah P&A operations did not begin until the first staff person was hired in January, 1978.

No state reported difficulty in finding facilities or equipment, some of which were contributed in-kind by parent agencies or other organizations.

P&A Case Volume and Measurement

Caseloads in the nine states reflect the start-up character of P&A agency operations. In the table

below, average monthly caseloads are shown. The appropriate range for each state was determined by taking the total cases reported as of mid-FY '78 and dividing by the total months of P&A operations to that date. This was an attempt to provide comparability among the states, since the actual number of cases varied from seven in Florida and Utah (after four months and one month of operations, respectively) to 227 in New Jersey (after 18 months) and 560 legal advocacy cases in Minnesota (after three years).

STATE	AVERAGE MONTHLY CASE VOLUME			
	≤ 5	6-10	11-15	16-20
Florida	•			
Idaho				•
Illinois			•	
Louisiana	•			
Maine			•	
Minnesota				•
New Jersey			•	
North Carolina		•		
Utah		•		

* Legal advocacy project only

While caseload data in the full report are as accurate as could be supplied by the P&A agencies, there are problems of comparability in the statistics which, unless addressed, will complicate any attempts to draw comparisons or explain P&A progress on a national, regional, or even statewide basis. For example:

- **"Case" definitions are not uniform.** In some states, all matters coming to agency attention, including brief information and referral calls, may be counted as cases. In other states, only matters requiring fairly intense service delivery by the agency may be counted. The Minnesota legal advocacy component, in contrast, classifies its cases as individual or group and as representation or consultation only. There also might be some merit to classifying cases not only as to number of people served, but as some combination of people and client objectives. For example, an individual

client may seek to secure housing and to challenge a matter of employment discrimination. Counting objectives of this type and their achievement has advantages that will be addressed here.

- **Average caseload measurements can be misleading.** One way to document average caseloads is shown in the table and involves the basic formula: "total cases to date" divided by "total units of time to date" (weeks, months, quarters, etc.). If a "case" equals an "individual", then the formula will yield the average number of new individuals served by an agency for a given unit of time. This figure can be misleading however, in terms of the actual volume of agency activities. For example, say that Agency A gets 10 new cases in its first month, that these remain the only P&A cases, and that they continue to receive attention through the sixth month when an average is to be calculated. Using the formula above, the average would be 10 cases ÷ 4 (full) months = 2½ cases per month. Agency B gets 10 cases in its first month; these are its only cases and they receive attention through the third month when the agency prepares its statistics. Average monthly caseload for Agency B is 10 cases ÷ 3 months, or 3⅓ cases per month. Assuming other things (e.g. case definitions, staff effort, etc.) were equal, weren't the two agencies handling identical case volumes each month? The answer is "yes" and the remedy to the counting problem is to record the average number of *open* cases per month. The simple formula for this would be: "total cases carried over previous time period" plus "total new cases in current time period" minus "total cases closed in current time period" equals "total number of open cases in current time period". Open cases for successive time periods can be added and their average can be found by dividing by the number of time periods. This provides a more realistic notion of agency activity than does the first type of average. The words "closed case" may present a problem to some agencies. At least one has noted that because of the ongoing nature of developmental disabilities, no case is considered "closed". This is where tracking client objectives can be useful, since the objectives are likely to vary over time for a given client, and their achievement can be documented even though the "case" remains open.

• **Caseload comparisons will be more valid when all P&A agencies are fully operational.** Comparing a start-up operation (e.g. one that has not yet conducted a major outreach or publicity effort) with an ongoing program can be misleading. For example, allowances must be made for the fact that Utah's legal advocacy program handled seven cases during one month, its first, and the Minnesota legal advocacy program handled 700 individual cases in one operating year (after devoting time in previous years to outreach and training, etc.). Similarly, Illinois' initial caseload cannot be compared to its later intake of about 200 cases per month when several program components were operational.

• **Similar case volume may result from very different resource investments.** This is the dilemma of comparing 10 cases in a \$100,000 agency to 10 cases in a \$1 million agency. If case volume is used as an evaluation criterion, average cost per case ought to be considered also. The simplest way is to divide total annual operating cost for an agency by the annual number of cases. Costs for specific types of cases may be derived by considering more subtle criteria such as: duration (elapsed time), frequency, and intensity of service effort (e.g., amount of time spent by various types of staff on case-related activities).

Other data useful for evaluation or program analysis purposes, but not currently available on a uniform basis, would be:

• **Client Identifying Information** — age and disability, and desirably: sex, race or ethnic group, living arrangement (independent, group, other residential, etc.), and other characteristics that might indicate whether or not specific target groups were being reached and were making use of the advocacy system.

• **Regional or Project Statistics** — (as applicable) as well as aggregate data for the state, since smaller breakdowns can assist agencies to monitor various P&A component operations

• **Records of Referrals to and from the P&A Agency** — the former can assist P&A personnel to monitor the referral network and to contact or-

ganizations that may not be making adequate use of advocacy services. Agencies and organizations receiving referrals from the P&A agency could be following-through with data collection similar to that conducted by the agency itself. This would allow the whole P&A system to be monitored. It also would be a difficult task where the P&A agency is referring to others with whom it has no formal agreements (and therefore no authority to request or demand data of a certain type).

Data Collection and Monitoring

Intake forms in varying degrees of detail were being used by seven out of nine P&A agencies at midyear. Based on their experience with service delivery and data collection at that point, three of the agencies (Idaho, Louisiana, New Jersey) already were adjusting their intake forms (e.g. in Idaho to eliminate unnecessary complexity). Maine retained client files but used no formal intake document, and the Utah agency had not yet developed a form. Actual caseloads were small in most agencies at the middle of the year, so there was little need for formality. Aside from basic client characteristics, most agencies recorded the nature of the problem or complaint brought to their attention and the action taken in the case. Staff of some agencies, such as those in Florida, Idaho and Minnesota, also maintained a separate log of daily activities.

Lists, directories, and files containing information on other advocacy organizations also were ready or were being prepared by most agencies for use in the referral process. Survey questionnaires for various purposes had been developed as well (e.g. in Florida, for preparation of its resource directory; in Minnesota, to determine advocacy needs and criminal justice system training needs).

Despite the fact that all agencies were collecting information of some type, only three at midyear had available statistics on clients and services or other aspects of agency operations. The three were those with the largest recorded caseloads: Idaho, Minnesota (legal advocacy component only) and New Jersey. Idaho's

caseload statistics were broken down in various ways (e.g. by region, by type of service or need, by disability, etc.). In addition, that state maintained statistics on referrals to and from the agency. Minnesota had equally detailed caseload statistics, as well as data on training (sessions, participants, etc.) and on referrals. New Jersey had caseload statistics (by nature of complaint) and like Minnesota, tracked open and closed cases.

Florida and North Carolina maintained case listings. No formal statistics were available from the remaining agencies; in these the directors could report total cases, but might estimate for example, what percentage were education cases. (Since this type of case was common, it is known that all agencies intervened in education; there is less certainty about what substantive areas were addressed in remaining cases.)

Not unlike the data collection process, monitoring of P&A operations was mostly an informal process at midyear. In a two-person agency, of course, line operations are not difficult to track. In larger agencies, e.g., in Idaho with its regional operations, data submitted by field advocates were reviewed weekly and problems, if any, could be discussed informally by phone or at staff meetings. Similarly, staff meetings in New Jersey were a forum for sharing information and discussing any problems. P&A directors in turn reported to governing bodies or to a superior (e.g. the head of the Department of the Public Advocate met fairly frequently, but informally, with New Jersey's P&A director). Plans existed in most states for formal reporting to DD Councils and/or to the Executive Office, but during the start-up period this too was largely informal (e.g. DD Council liaisons sit on several of the P&A boards and/or a P&A representative attends DD Council meetings). Audits of contract operations were discussed in P&A Plans, but formal program or fiscal audits were neither discussed nor, in any significant degree, ready for launching by those interviewed.

In addition to questions regarding oversight for internal agency and contract/grant operations, there is an issue of equal importance: monitoring the advocacy performance of the voluntary and public organizations that, along with the P&A agency, are meant to form an advocacy system.

Clearly, no one agency — and certainly none among the smallest or least endowed — can constitute a system as envisioned by P.L. 94-103. This was recognized in most of the state DD advocacy Plans developed as a condition for P&A funding. (Plans specified the various voluntary and public organizations that would be relied on for assistance in delivery of advocacy services.) The problem of network monitoring is not a simple one since the P&A agencies in most cases have no formal authority over any but their own actions. This issue may become more clear and will remain worthy of attention as implementation proceeds.

Summary Observations

The information generated by this study gives rise to a number of issues worthy of consideration by those who next study the P.L. 94-103 Protection and Advocacy program and those who formulate and execute the policies governing that program at national, state and local levels. Significant findings and issues include the following:

- P&A system independence from state government as well as service provider influence is a concern raised by both public and private agencies; there has been apprehension, for example, about governors' reactions to P&A activism and about the possibility of compromise (or the appearance of compromise) associated with accepting some sources of funds, including those from state DD Councils.

- While implementors are concerned that P&A expansion will depend ultimately on their ability to mobilize "neutral" sources of funds, this has not been a major problem in the first year:

- On the average, implementing agencies in the sample states have more than doubled the FY '78 allotments made to them under P.L. 94-103 by obtaining other government and private revenues.
- All sample states have garnered in-kind con-

tributions (facilities, staff-time, etc.) whose value in some cases is substantial (e.g., an estimated \$33,000 for the year in Idaho, \$63,000 in Minnesota, over \$100,000 in Illinois).

- Most states were actively seeking additional resources (money, staff) by midyear; thus current resources were, in part, devoted to generating future resources.

- Despite their success in mobilizing non-P.L. 94-103 resources, most agencies were concerned that these would be inadequate to meet actual demand for advocacy services:

- The potential effect of publicity and outreach efforts (still quite limited in the first year) on the demand for services was seen as a problem in most states; demand already exceeds capacity in at least one jurisdiction

- The problem of response to rising demand is exacerbated where auxiliary resources (volunteer networks, consumer groups, etc.) are small, poorly organized, in conflict, and/or non-existent in some or all parts of a state. (Each of these conditions existed in one or more of the sample states and the feasibility of creating true advocacy "systems" under continuing circumstances of this kind is subject to question.)

- There is concern in some states that advocacy not be expanded to groups other than the developmentally disabled unless or until such demand and capacity problems are resolved. (Some have urged that expansion of the P&A program to groups such as the mentally ill and/or the physically handicapped not be considered unless 1) identifiable resources are allocated to the developmentally disabled and 2) sufficient total resources are made available.)*

- However great or small their pool of resources for fiscal year 1978, nearly all sample states by the middle of that initial year had been involved not only in "individual advocacy", but also in "systems advocacy" efforts such as planning, administrative

rule-making or community organization around specific substantive issues.

- Legal services were provided directly or through grant/contract operations in seven of the sample states, and were available only under informal referral arrangements in the other two. In these (Idaho and Maine) and in an additional state (New Jersey) some or all legal cases must be referred to general purpose legal aid or legal services offices, requiring clients above the legal aid income cut-off point to seek out private attorneys (with occasional but limited P&A agency referral services).

- All sample states by the middle of the year had handled client cases in a variety of substantive areas (such as education, zoning and guardianship), and the variety and volume had increased by year-end:

- P&A intervention in all states included client representation at administrative hearings

- By the end of the year, P&A cases in seven states had resulted in some court action, including but not limited to, class action litigation in two or three states

- Litigation generally was and is viewed as a last resort, with out-of-court negotiation and informal attempts at complaint resolution deemed the more desirable and least time-consuming alternatives

- Data on P&A agency activities and clients were improving throughout the year, but evaluation of the P&A program nationally may be hampered significantly by the lack of comparable data among states (e.g., caseload data, service classifications, output measures, operational statistics, etc.)

- As data collection improved during the first year, agencies appeared better able to monitor line operations, but the monitoring process in

* Addressing the same issue, the President's Commission on Mental Health, in its final report earlier this year, recommended the establishment of comprehensive advocacy systems for the mentally ill (proposing P.L. 94-103 as a model); legislation to the same effect was introduced in the 95th Congress.

most states remained informal and, short of documenting referrals, P&A agencies had little authority and few tools for monitoring the activities of organizations or individuals outside the agencies' direct administrative control. This situation, along with other difficulties in integrating outside advocacy resources, threatens the development of viable advocacy systems as envisioned by P.L. 94-103.

By and large, it appears that the statewide advocacy systems contemplated by the Developmentally Disabled Assistance and Bill of Rights Act, at least in the profile states examined here, accomplished the difficult business of organizing and "opening the store" in their inaugural year, and that they did this with energy, commitment

and as much speed as might be expected of a program with such ambitious scope, limited resources, and broad client and service diversity. While significant policy and operations issues have emerged during the first year, future years will provide the main testing ground for program success and viability. It is to be hoped that those responsible at all levels for the now-launched P&A experiment will meet that challenge with dedication, capability and a keen eye to embracing the necessary adjustment and "fine tuning" that often spell the difference between effectiveness and failure in complex service programs such as these. To the extent that this occurs, the nation may achieve a victory for the interests of developmentally disabled citizens and the broader arena of comprehensive client advocacy that will stand a model for years to come.

About . . .

The Commission on the Mentally Disabled

The American Bar Association Commission on the Mentally Disabled is a 17 member interdisciplinary body established in 1973 to initiate, on behalf of the Association, a public service program to foster improvements in the nation's mental disability system.

The Commission operates five action programs, all supported by private foundation or government funds: the Mental Disability Legal Resource Center (publishes the *Mental Disability Law Reporter* and provides technical support to those involved in mental disability law change), the Developmental Disabilities State Legislative Project (produces model laws and commentary to advance rights and protections for the developmentally disabled), the Bar Activation/Bar Funding Program (encourages state and local bar associations to work for mental disability system reform and awards modest project grants for legal services projects in the field), and the Pennsylvania Mental Health Advocacy Project (provides institutional legal services in three Pennsylvania state hospitals and is now expanding to become an independent statewide system of such services).

Commission activities have also included submission of *amicus* briefs in leading Supreme Court cases on mental disability commitments, drafting of ABA policy positions on restrictive zoning laws regarding community group homes, on implementation or rights of the mentally disabled, and on legal services and advocacy for this groups, submission of testimony at congressional hearings on rights of the mentally disabled, and generally attempting to involve the nation's lawyers in this critical field.

About . . .

The ABA Public Service Activities Division

Throughout its history, one of the goals of the ABA has been to apply the knowledge and experience of the legal profession to promotion of the public good. This objective now pervades virtually every activity of the Association. It is also the exclusive and overriding mission of the ABA's Division of Public Service Activities (PSA), one of the major program divisions which provides staff support for the Association's many attorney-sponsored programs and activities. Within the ABA, seven committees, four interdisciplinary commissions, and one membership section are served by the Division. These are:

- Section of Individual Rights & Responsibilities
- Commission on Law and the Economy
- Commission on Legal Problems of the Elderly
- Commission on Medical Professional Liability
- Commission on the Mentally Disabled
- Council on Legal Education Opportunity
- Committee on Environmental Law
- Committee on World Order Under Law
- Committee on Housing & Urban Development Law
- Committee on Energy Law
- Committee on Election Reform

Through these units, the ABA studies a variety of issues and formulates remedial responses ranging from policy positions through study reports, clearinghouse efforts, demonstration projects, public education initiatives and working conferences. These activities are advanced within the Division by a support staff of over thirty persons and an annual budget of over \$3 million, much of which is derived from federal and private foundation grants. The "volunteers" who direct these endeavors and guide Divisional work are primarily, but not exclusively, lawyer members of the ABA. They include distinguished legal scholars, legislators, judges, private practitioners, public interest lawyers, corporate presidents, governmental analysts, eminent doctors, scientists, and economists.

The day when lawyers and judges could confine themselves sedately to deeds, wills, trusts, and matters of commerce is gone. They must increasingly devote their special skills and talents to the large problems of community and national concern.

Warren E. Burger — 1969